Symptoms, functioning and coping strategies in individuals with schizophrenia spectrum disorders who do not take antipsychotic medication: a comparative interview study

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Background. A considerable proportion of people with schizophrenia spectrum disorders do not take antipsychotic medication but seem to be functioning well. However, little is known about this group. To test the assumption that absence of medication is compensated for by more effective coping and increased social support, this study compared symptoms, functioning, coping strategies and social support in non-medicated and medicated individuals with schizophrenia spectrum disorders.

Method. In all, 48 participants with a DSM-IV schizophrenia spectrum disorder who were taking (n = 25) or not taking antipsychotic medication (n = 23) were included. Assessment consisted of self-ratings of symptoms, symptom-related distress and social support combined with a semi-structured interview that assessed general and social functioning, subjective evaluation of symptoms and coping strategies.

Results. Symptom severity and distress did not differ between the groups. However, the non-medicated participants had significantly higher levels of general functioning than medicated participants and a longer duration of being non-medicated was significantly associated with a higher level of general functioning. In contrast to the hypotheses, not taking medication was not associated with more effective coping strategies or with higher levels of social support. Medicated participants more frequently reported the use of professional help as a coping strategy.

Conclusions. Our results corroborate previous studies finding improved functioning in individuals with schizophrenia spectrum disorders who do not take medication compared with those who take medication, but do not support the notion that this difference is explicable by better coping or higher levels of social support. Alternative explanations and avenues for research are discussed.

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Introduction

Prolonged treatment with antipsychotic medication (AM) is widely considered as the standard care in patients with schizophrenia (Buchanan *et al.* 2010). From the patients' perspective, the wish to lead a normal life and to cope with occurring symptoms is the main reason for taking AM (Moritz *et al.* 2014). Indeed, AM has been shown to be effective in reducing symptoms, increasing short-term functioning, and preventing relapse (Leucht *et al.* 1999, 2009, 2012). However, overall effect sizes are moderate at the

most (Leucht *et al.* 2009) and up to 74% of the patients do not take their medication as prescribed (Lacro *et al.* 2002; Lieberman *et al.* 2005). Although predictors and consequences of incomplete medication adherence have been widely studied (e.g. Lacro *et al.* 2002; Ascher-Svanum *et al.* 2006; Wiesjahn *et al.* 2014), comparatively little is known about patients who do not take AM at all or have long medication-free periods. This is surprising as complete non-adherence is not a rare phenomenon. For example, in an international study combining World Health Organization surveys, Harrison *et al.* (2001) identified an average of 26% of the patients with psychosis as not to have been taking AM at all for at least 2 years.

In a prospectively designed investigation of all patients admitted to two Chicago hospitals with a first or second episode of schizophrenia or schizo-affective

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disorder, Harrow et al. (2012) found that about 35% of the patients initially treated with AM terminated medication intake within 2 years and stayed off medication for the following 18 years. Interestingly, this selfselected group had significantly higher levels of general and social functioning, lower levels of symptoms, and more periods of recovery than the continuously medicated sample at all follow-up assessments (after 4.5, 7.5, 10, 15 and 20 years) although the groups did not differ significantly in these variables at baseline. It needs noting, though, that the non-medicated group showed better early pre-morbid developmental achievements related to work, education, marital status (among others) and better prognostic factors, such as acute onset or precipitating stress at index hospitalization (Harrow & Jobe, 2007; Harrow et al. 2012). Thus, these factors might be predictors for being successfully off medication in the long run. In line with the Chicago study, Moilanen et al. (2013) identified 34% of the patients with schizophrenia spectrum disorders of the Northern Finland 1966 birth cohort sample as being non-medicated. All of these non-medicated participants had been hospitalized at least once and the majority had withdrawn from AM more than 1 year ago. Compared with the remaining medicated sample, these patients revealed lower symptom scores, better functioning, were less often in a disability pension, and had spent less time in psychiatric hospitals.

These studies indicate that there are patients who do not take AM in order to reduce symptoms, but nevertheless do not seem to be fairing worse in the long run than those who take AM. This raises the question, among many others, whether this group of patients compensates for the absence of medication by increasing their use of other potentially helpful strategies. In an exploratory interview trial, McNally & Goldberg (1997) found social support strategies, such as calling a friend, behavioural distraction, professional help and cognitive strategies to be widely used coping strategies of patients with schizophrenia. However, little is known about which coping strategies are used by nonmedicated individuals. It seems intuitive to assume that they might draw more strongly on social support, a factor known to predict better clinical and functional outcomes (Erickson et al. 1998; Norman et al. 2005) or use other coping strategies in a more effective manner. This assumption is underpinned by the results of Torgalsboern (2012) who found a positive correlation between the level of functioning and greater resilience, which can be defined as the ability to cope successfully with stress (Connor & Davidson, 2003), in nonmedicated patients with schizophrenia.

In the present study we thus compared sociodemographic and clinical variables, as well as social support, and coping behaviour in non-medicated and medicated persons with schizophrenia spectrum disorders. Following the results of the Chicago (Harrow *et al.* 2012) and the Northern Finland (Moilanen *et al.* 2013) studies, we expected that individuals not taking AM would show lower symptom severity and better functioning than those on medication. Furthermore, based on the assumption that non-medicated individuals compensate for the absence of medication by using other coping strategies and draw more strongly on social support as a way of coping, we expected them to show a wider range of coping strategies than patients who take medication, to be more satisfied with the effect of these strategies and to receive more social support.

As an additional research question, we aimed to explore on a qualitative level which types of coping strategies participants use and whether non-medicated and medicated individuals differ in the types of strategies employed.

Method

Participants and study setting

The study took place at the Philipps University of Marburg and the University of Hamburg, Germany. Participants were recruited via advertisements in local newspapers and bulletin boards in public spaces as well as on non-profit Internet platforms on psychotic disorders in the German language (http://www.kompetenznetz-schizophrenie.info/forum/; http://www.schizophrenie-netz.info/forum/). The study was also promoted in the out-patient clinic of the University of Marburg and in the Psychosis Outpatient Clinic of the Psychiatric Hospital of the University of Hamburg.

The trial was approved by the Ethical Committee of the Department of Psychology of the University of Marburg (AZ 2011–22k). Informed consent was obtained from all participants or their legal guardian. Inclusion criteria were: (1) having a schizophrenia spectrum psychotic disorder (schizophrenia, schizoaffective disorder, delusional disorder, psychotic disorder not otherwise specified) confirmed by the Structured Clinical Interview for DSM-IV (SCID; Wittchen *et al.* 1997); (2) not taking AM for at least 3 months (non-medicated sample) or taking AM for at least 3 months (medicated sample); (3) age between 18 and 70 years; (4) sufficient German language skills to communicate with the interviewer.

Measures

We generated a semi-structured interview to assess diagnosis, previous and current symptoms, subjective evaluation of symptoms, history of mental disorder, experiences with medication, experiences with the psychiatric health care system, and coping strategies. In addition, we assessed insight, illness beliefs, reasons for taking or not taking medication, and the relationship with the treating physician, which will be reported elsewhere. Each topic was explored by open-ended questions and the answers were rated by the interviewer on four- or five-point rating scales (e.g. 'Do you have specific strategies for coping with symptoms?'; 'On the whole, are your coping strategies working sufficiently well? Rating scale: 1 = no; 2 = rather no; 3 = rather yes; 4 = yes). The complete interview can be retrieved from the corresponding author (T.M.L). In order to increase the validity of the interview ratings, all interviews were rated again by a student assistant trained in rating the interview scales and blind to the hypotheses. Blinding on group membership was not possible as this was explicit in the interview. The analyses are based on a consent rating between interviewer and second rater.

The presence of psychotic disorder was assessed using the SCID (Wittchen et al. 1997), sections B and C, which were integrated into the interview.

Psychotic symptoms and symptom-related distress were assessed using the German version of the Community Assessment of Psychotic Experiences (CAPE; Konings et al. 2006). This self-rating instrument consists of 42 items on the three dimensions of positive symptoms, negative symptoms and depression. Symptoms are rated with regard to frequency of occurrence and related distress. The German version has demonstrated good internal consistencies ($\alpha = 0.84$ -0.91; Lincoln et al. 2009).

We used the DSM Axis V Global Assessment of Functioning Scale (GAF) as a global measure of social, psychological and occupational functioning (Sass et al. 2003), which has been shown to be valid for assessing global functioning in patients with schizophrenia (Schwartz, 2007).

Social functioning was assessed with the Role Functioning Scale (RFS; Goodman et al. 1993), which has demonstrated good criterion validity and retest reliability (0.85–0.92 within a 1-year period). Ratings are based on a semi-structured interview. We used an adapted version of the RFS with anchoring points ranging from 1 to 12 (Lincoln et al. 2012), referring to the last 7 days and combined the subscales 'immediate social network relationships' and 'extended social network relationship' to a composite score.

Perceived social support was assessed using the short version of the Social Support Questionnaire (Fydrich et al. 2009). This 14-item instrument has demonstrated excellent internal consistency (α = 0.94; Fydrich *et al.* 2009).

Procedure

Participants contacted the authors by telephone. After a brief telephone screening, participants were invited

for the interview session. They provided informed consent and completed a demographic questionnaire, followed by the interview and the remaining questionnaires. Three interviewers were involved in the study (E.J., M.W., H.W.). All interviews were video- or audiotaped. The complete assessment took about 2 h. Participants received 15 Euros for their participation.

Analyses

Data were analysed using SPSS version 21.0.0 (USA). We tested the distribution of the variables separately for the non-medicated and medicated groups. As several variables were not normally distributed according to the Kolmogorov-Smirnov test, we used parametric as well as non-parametric procedures. In order to avoid inflation of type 1 error, we applied Bonferroni corrections. For non-parametric tests r is reported as effect size (0.1 = small; 0.3 = medium; 0.5 = large; Field, 2009). For parametric tests we reported Cohen's d (0.2 = small; 0.5 = medium; 0.8 = large; Cohen, 1992).

Additionally, we used qualitative methods to analyse coping strategies. Two authors (E.J., M.W.) went through the list of reported strategies independently and identified categories of strategies. In the next step, the identified categories were compared and discussed until consensus on categories was reached. One author coded the strategies according to the final set of categories.

Results

Sample characteristics

In total, 51 participants were recruited, 47% in Marburg, 53% in Hamburg. About half of the participants had been invited to participate by their therapist (51%), 45% responded to the advertisement, and two participants were referred by a friend. Three participants were excluded from the analyses because they did not meet the criteria for a schizophrenia spectrum disorder, although they reported subclinical delusions or hallucinations.

Of the remaining 48 participants, 33 participants (69%) fulfilled DSM-IV criteria for schizophrenia, 10 (21%) for schizo-affective disorder, and five (10%) for delusional disorder.

A total of 23 participants had not taken AM for at least 3 months; 25 were taking AM. The mean age of participants was 43.40 (s.d. = 12.65) years; 44% were female. The mean duration of disorder was 15.14 (s.D. = 11.06) years. The groups did not differ significantly in sex, age, family status, educational level, diagnosis or duration of psychosis (see Table 1). Medicated

Table 1. Sociodemographic and clinical characteristics for non-medicated and medicated participants

	Non-medicated $(n = 23)$	Medicated $(n = 25)$	Statistics	
Characteristics	Mean (s.d.) or %	Mean (s.d.) or %		
Sex, %			$\chi^2_1 = 0.01, p = 0.601$	
Male	56.5	56	•	
Female	43.5	44		
Age, years	42.52 (12.85)	44.20 (12.67)	$t_{46} = 0.46, p = 0.651$	
Family status, %			•	
Married or partner	13	12	$\chi^2_2 = 2.12, p = 0.714$	
Single	61	72		
Divorced	26	16		
Duration of education, years	17.39 (4.19)	16.10 (3.47)	$t_{42} = -1.12$, $p = 0.270$	
Education final level ^a , %				
Low	4.3	12.5	$\chi^2_2 = 1.19, p = 0.708$	
Medium	30.4	33.3		
High	65.2	54.2		
Main diagnosis, %				
Schizophrenia	65.2	70.8	$\chi^2_2 = 5.60, p = 0.133$	
Schizo-affective	17.4	29.2		
Delusional disorder	17.4	0		
Duration of psychosis, years	13.15 (10.03)	16.98 (11.84)	$t_{46} = 1.20, p = 0.236$	
Current treatment, %				
Psychiatric out-patient treatment	21.7	93	$\chi^2_1 = 24.33, p < 0.001$	
Psychological out-patient treatment/therapy	26.1	56	$\chi^2_1 = 4.50, p = 0.025$	
Psychiatric hospital	0	4.2	$\chi^2_1 = 0.94, p = 0.332$	
Previous treatment, %				
Psychiatric out-patient treatment	47.8	97	$\chi^2_1 = 14.10, p < 0.001$	
Psychological out-patient treatment/therapy	52.2	72	$\chi^2_1 = 2.01, p = 0.156$	
Psychiatric hospital	69.6	100	$\chi^2_1 = 8.90, p = 0.003$	
Number of in-patient hospitalizations	4.63 (6.72)	6.36 (6.16)	U = 127, $z = -1.97$, $p = 0.401$	
Patients with legal guardian, %	8.7	16	$\chi^2_1 = 0.58, p = 0.445$	

s.d., Standard deviation.

participants were more likely to be in psychiatric (93% v. 21%; p<0.001) and psychological out-patient treatment (56% v. 26%; p=0.025). Also, in the medicated sample more participants had previously been in psychiatric out-patient and in-patient treatment (97% v. 48% and 100% v. 70%, respectively; p<0.001).

Of the non-medicated participants, 78% had previously taken AM. Three of these participants had withdrawn within the last year, four had been off medication for 1–5 years, four for 5–10 years and five had withdrawn more than 10 years ago. About half of these participants (55%) reported that discontinuation of AM had been in agreement with their treating physician. On average, these participants had been on medication for 30.8 (s.d. = 36.2) months, ranging from 1 week to 9 years, and had discontinued AM on average 8 years ago (mean = 93.7 months, s.d. = 101.4, range = 3–336 months). Five participants (22%) had never taken

AM. Two of them had been offered AM but refused; three had never seen a psychiatrist and had never been offered AM.

Psychopathology, general functioning and distress

As can be seen in Table 2, the groups did not differ significantly in positive symptoms, negative symptoms, or symptoms of depression. Non-medicated participants had significantly higher levels of general functioning (GAF) than medicated participants (p = 0.04; d = -0.63). There were no significant differences in the level of social functioning, symptom-related distress, or evaluation of symptom experiences. In both groups, the majority of participants reported to perceive the symptoms as being 'rather distressing' or 'distressing', with a tendency towards more perceived distress in non-medicated participants.

^a Low = Hauptschule (general secondary school); medium = Realschule (intermediate secondary school); high = Abitur (A-level or high school equivalent).

Table 2. Symptom severity, level of functioning, symptom-related distress, and subjective evaluation of symptoms in non-medicated and medicated participants

	Non-medicated	Medicated	Statistics	Effect size
Symptoms ^a				
CAPE Positive	30.41 (11.88)	28.00 (9.46)	U = 238.00, $z = -0.79$, $p = 0.429$	r = -0.12
CAPE Negative	24.59 (7.34)	24.04 (6.98)	U = 260.50, $z = -0.31$, $p = 0.756$	r = -0.05
CAPE Depressive	14.52 (5.92)	13.12 (4.04)	U = 252.50, $z = -0.48$, $p = 0.630$	r = -0.07
General functioning			ŕ	
GAF	61.35 (15.20)	53.68 (8.72)	$t_{46} = -2.12, p = 0.040$	d = 0.63
Social functioning				
RFS	7.67 (2.92)	7.88 (2.26)	$t_{46} = 0.28, p = 0.785$	d = 0.10
Symptom-related distress ^a				
CAPE Distress positive symptoms	54.05 (26.32)	33.24 (28.06)	U = 125.50, $z = -1.91$, $p = 0.056$	r = -0.29
CAPE Distress negative symptoms	34.35 (14.93)	27.91 (13.17)	U = 170.00, $z = -1.87$ $p = 0.062$	r = -0.28
CAPE Distress depressive symptoms	20.85 (9.59)	17.14 (8.06)	U = 179.00, $z = -1.47$, $p = 0.141$	r = -0.22
Evaluation of symptoms			·	
How do you evaluate your symptoms? ^b	2.17 (1.47)	2.16 (0.99)	U = 259.50, $z = -0.61$, $p = 0.545$	r = -0.09

Data are given as mean (standard deviation).

CAPE, Community Assessment of Psychotic Symptoms (higher scores indicate more severe symptoms and distress); GAF, Global Assessment of Functioning Scale (higher scores indicate better functioning); RFS, Role Functioning Scale (higher scores indicate better functioning).

Table 3. Group comparisons on social support, number and evaluation of coping strategies^a

	Non-medicated	Medicated	Statistics	Effect size
Social support Number of coping strategies ^b Sufficient number of strategies? ^{b,c} Are strategies working satisfyingly? ^{b,c}	3.30 (1.13) 4.00 (1.71) 3.62 (0.50) 3.35 (0.75)	3.71 (0.76) 4.32 (1.60) 3.63 (0.65) 3.16 (0.99)	$t_{45} = 1.23, p = 0.223$ U = 263.50, z = -0.51, p = 0.612 U = 209.00, z = -1.32, p = 0.188 U = 237.50, z = -0.40, p = 0.689	d = 0.35 $r = -0.01$ $r = -0.19$ $r = -0.06$

Data are given as mean (standard deviation).

Social support and coping strategies

The groups did not differ significantly in the level of perceived social support (p = 0.22; d = 0.35; see Table 3).

Except for one, all participants reported using at least one coping strategy, with a mean of 4.17 (s.d. = 1.64) strategies. The groups did not differ significantly in the number of reported coping strategies or in their satisfaction with the quantity and effectiveness of these strategies (see Table 3). In both groups the majority of participants (>70%) were 'rather satisfied' or 'satisfied' with the number of strategies and the way they worked.

As can be seen in Table 4, the qualitative analysis revealed eight categories of coping strategies. Participants in both groups reported using general selfcare strategies most frequently, followed by cognitive strategies, distraction, social and physical strategies (11-15 times). Substance strategies (excluding medication use) and religious or spiritual practice were rarely reported. Medicated participants reported professional help strategies (n=10) significantly more often than non-medicated participants (n = 1, $\chi_1^2 = 8.62$, p = 0.005). With this exception, distribution of reported strategies was comparable across the groups (see Table 4).

^a Bonferroni corrected level of significance: p<0.017. We applied Bonferroni corrections within blocks of analysis.

b'How do you evaluate your symptoms? As being "negative" (1), "rather negative" (2), "neutral" (3), "rather positive" (4), or "positive"?'.

^a Higher scores indicate more perceived social support and higher satisfaction with strategies.

^b Bonferroni corrected level of significance: p < 0.017.

^c Rating scale ranging from 1 = no; 2 = rather no; to 3 = rather yes; 4 = yes.

Table 4. Frequencies of reported categories of coping strategies in non-medicated and medicated participants

Category	Subcategory and/or examples	Non-medicated	Medicated
Distraction	e.g. listening to music, watching television	13	13
Social strategies	e.g. meeting friends, talking about experiences	11	12
Cognitive strategies		25	17
	Cognitive techniques, e.g. reality check, questioning cognitions	12	12
	Self-reflection/reflection of experiences; e.g. writing diary	7	2
	Acceptance, e.g. accepting presence of symptoms or unpleasant emotions	6	3
Self-care strategies		26	29
	Healthy lifestyle; e.g. well-structured daily routine; stick with the job	13	15
	Withdrawal and recreation; e.g. leaving straining situations; having a break	11	11
	Relapse prevention, e.g. monitoring warning signs for relapse	3	3
Physical strategies		11	15
	Physical training; e.g. running, dancing	8	12
	Relaxation techniques; e.g. breathing relaxation, yoga	3	3
Substance consume ^a	e.g. drinking alcohol; consuming cannabis	2	3
Seeking professional help Religious/spiritual strategies	e.g. calling the therapist; visiting therapy group; calling help-hotline	1	10
	e.g. praying; meditation; believe in a benevolent companion	5	1
Total		95	100

^a Excluding use of medication (e.g. adapting dosage of antipsychotic medication, using additional medication, using homeopathic medication) which was reported seven times in the medicated group and once in the non-medicated group.

We found significant positive bivariate correlations between satisfaction with the quantity and effectiveness of strategies and the level of general functioning (r=0.39, p=0.008 and r=0.36, p=0.015). The satisfaction with the quantity of strategies was also significantly associated with social functioning (r=0.33, p=0.024). However, there were no significant relationships between the numbers of reported coping strategies and levels of general (r=0.14, p=0.138) or social functioning (r=0.07, p=0.351).

Subgroup analyses of non-medicated participants

Never taken AM v. previously medicated

Those participants who had never taken AM (n=5) had significantly lower depression scores (median= 10.00) than those who had been medicated in the past (n=18) (median=15.47, U=14.00, z=-2.25, p=0.025). The groups did not differ significantly in psychotic positive or negative symptoms, general or social functioning, social support or number of coping strategies.

Withdrawn from medication in agreement with physician v. without physician

There were no significant differences between those who had withdrawn from medication in agreement

with the treating physician (n = 10) and those who had withdrawn without a physician (n = 8) concerning the number of previous hospitalizations, symptom severity, functioning, social support, or number of coping strategies (all p > 0.05).

Time off medication in relation to duration of disorder

A longer duration of being non-medicated (in relation to the duration of the disorder) was significantly associated with higher general functioning (r = 0.53, p = 0.023). No other significant associations were found.

Discussion

In corroboration of previous findings (e.g. Harrow & Jobe, 2007; Harrow *et al.* 2012; Moilanen *et al.* 2013), non-medicated participants revealed a higher level of general functioning than the medicated individuals. Moreover, we found that the longer a participant had been off medication (in relation to the duration of disorder), the higher his or her level of general functioning was. This is in line with the notion that not taking AM is more likely to show advantages over a longer time course than on a short-term basis (Whitaker, 2004; Harrow & Jobe, 2013).

Interestingly, however, despite their somewhat higher levels of functioning, the non-medicated participants revealed similar symptom severity and a tendency towards more symptom distress. Although the finding that the participants who chose to discontinue medication are not more symptomatic than those who continue taking AM seems to imply that these patients are more capable of coping effectively with their symptoms, this hypothesis was not supported by our data that showed a comparable quantity and similar types of strategies between the groups.

The mean number of reported coping strategies was comparable with previous findings (Phillips et al. 2009), as were the types of strategies (Lee et al. 1993; Rückl et al. 2012). One exception was the use of professional help, which was – unsurprisingly – more often reported in the medicated sample. Furthermore, the majority in both groups was satisfied with the number and perceived effectiveness of coping strategies, and the extent of satisfaction was associated with better functioning. Due to the cross-sectional design of the study it remains unclear whether the higher level of functioning is a result of better coping or if greater satisfaction with coping is due to the more satisfying level of functioning. Moreover, self-efficacy might moderate or mediate the association between coping and outcome. It seems likely that persons with a schizophrenia spectrum disorder need confidence in their ability to cope with their symptoms for making the decision to withdraw from medication. Thus, non-medicated individuals might have higher self-efficacy beliefs. However, this remains speculative and warrants further research.

Some previous studies have indicated that higher functioning in non-medicated individuals with psychosis is associated with a better pre-morbid development or milder forms of psychosis (Harrow & Jobe, 2007; Moilanen et al. 2013). Sociodemographic and clinical data in our study do not support this assumption, as the groups did not differ in regard to their levels of education, duration of psychosis, number of previous hospitalizations, or psychotic diagnoses. Merely the finding that those who had never taken AM had lower depression scores than those who had previously taken AM points to a possible predictor for successfully being off medication in the long run. However, a number of possibly relevant factors (e.g. family history, neurobiological markers) that might explain higher functioning in non-medicated individuals were not assessed in this study due to its focus on coping and the cross-sectional design limit the study's validity in regard to explaining predictors of outcome.

Taking into account the common side effects of AM such as sedation or akinesia (e.g. 'feeling slowed down'; 'feeling like a zombie'; Weiden & Miller, 2001), an alternative explanation for higher functioning in non-medicated participants is that medication itself impairs functioning in those individuals who experience these restraining side effects (see Lewander, 1994 for a discussion of the neuroleptic deficit syndrome). However, reverse causation (individuals with poorer functioning and higher symptom level consequentially stay on medication) is also possible.

The treatment recommendation in current consensus guidelines for patients with first episode of schizophrenia is an initial treatment with AM for 1-2 years (Buchanan et al. 2010; Barnes & Schizophrenia Consensus Group of British Association Psychopharmacology, 2011). However, in clinical praxis AM is commonly prolonged for many years (Harrow & Jobe, 2007), which also becomes apparent in our sample, as medicated participants had been taking AM for 6.5 years on average, ranging from 3 months to 21 years. Together with the results of longitudinal trials that find better long-term outcomes in non-medicated compared with medicated patients (Harrow et al. 2012; Moilanen et al. 2013) and the findings on the severe risks of long-term use of AM (e.g. Newcomer & Haupt, 2006; Newcomer, 2007; Daumit et al. 2008; Ray et al. 2009; Ho et al. 2011), findings that show that patients who discontinue medication are doing equally well or better stress the necessity to be more courageous when it comes to discontinuing medication after a first acute phase. This conclusion is also clearly underpinned by the result of Wunderink et al. (2013) who found better long-term recovery rates in a group of first-episode patients with early dose reduction compared with a maintenance group after a 7 year follow-up.

Interestingly, subgroup analysis of our data revealed that participants who had withdrawn from AM on their own did not differ from those who had withdrawn in agreement with the treating physician with regards to symptom severity, functioning or numbers of hospitalizations. This is surprising, as sudden withdrawal from AM has generally been found to be associated with increased risk of relapse (Viguera et al. 1997). Our results indicate that there are patients who are able to withdraw responsibly and successfully from medication on their own. However, given the small numbers involved in the subgroup analyses, this finding warrants replication before drawing firm conclusions.

Limitations

Our sample size was small, which limited the power of our analyses and the generalizability of our results. Further, a selection effect for the complete sample has to be considered. It can be assumed that individuals with better coping capabilities and functioning were motivated to participate, as the 2 h assessment might have been too demanding for those with lower functioning. This might be the case for the unmedicated sample, in particular, of which a larger number was recruited by adverts rather than via out-patient facilities. Another limitation is the cross-sectional design. Randomized controlled longitudinal studies are needed to identify predictors for being successfully off medication in the long run. For clinical praxis, this would be a relevant progress and a step towards evidence-based individual decision making. This study only assessed spontaneously reported coping strategies, which might have underestimated the number of actually used coping strategies. Ambulatory assessment of symptoms and coping would allow more exact evaluation of coping and perceived effectiveness (Fahrenberg et al. 2007). A further limitation is that raters were not blind to groups, and interviewers were not blind to the hypothesis, which includes the risk of bias. However, the second rater was blind to the hypothesis and aims of the study and all analyses are based on the consensus ratings between the first and second raters, thus minimizing risk of bias. Furthermore, a substantial part of the analysed variables is based on self-ratings and is thus unlikely to be affected by possible rater bias.

Conclusions

In line with previous results our data indicate that for a subgroup of individuals with schizophrenia spectrum disorders it is possible to function well without AM. However, this does not seem to be explicable by more effective coping. Nevertheless, our results point to the availability of successful coping strategies in both non-medicated and medicated individuals with schizophrenia spectrum disorders and demonstrate that coping is associated with better functioning. Thus, clinicians and counsellors working with individuals with schizophrenia spectrum disorders are welladvised to explore and help to improving coping capabilities in order to increase resilience and functioning. In the light of severe side effects of long-term treatment with AM more research on predictors for successfully being off medication in the long run is needed in order to enable individual evidence-based counselling and to provide a basis for an informed and shared decision on treatment.

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Declaration of Interest

None.

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